

1 AN ACT in relation to public health.

2 Be it enacted by the People of the State of Illinois,
3 represented in the General Assembly:

4 Section 5. The Phenylketonuria Testing Act is amended by
5 adding Section 1.5 and changing Section 2 as follows:

6 (410 ILCS 240/1.5 new)

7 Sec. 1.5. Definitions. In this Act:

8 "Expanded screening" means screening for all genetic and
9 metabolic disorders, including but not limited to amino acid
10 disorders, organic acid disorders, fatty acid oxidation
11 disorders, and other abnormal profiles, in newborn infants
12 that can be detected through the use of a tandem mass
13 spectrometer.

14 "Tandem mass spectrometer" means an analytical instrument
15 used to detect numerous genetic and metabolic disorders at
16 one time.

17 (410 ILCS 240/2) (from Ch. 111 1/2, par. 4904)

18 Sec. 2. The Department of Public Health shall administer
19 the provisions of this Act and shall:

20 (a) Institute and carry on an intensive educational
21 program among physicians, hospitals, public health nurses and
22 the public concerning the diseases phenylketonuria,
23 hypothyroidism, galactosemia and other metabolic diseases.
24 This educational program shall include information about the
25 nature of the diseases and examinations for the detection of
26 the diseases in early infancy in order that measures may be
27 taken to prevent the mental retardation resulting from the
28 diseases.

29 (a-5) Require the physician or other health care
30 provider attending a pregnant woman at the diagnosis of her

1 pregnancy to (i) notify the woman that there are expanded
2 screening tests for metabolic and genetic disorders that may
3 be given to her child in addition to those tests required by
4 the State and (ii) provide that information to the woman in
5 writing within 7 days after the diagnosis of the pregnancy.

6 The Department shall also require the physician or other
7 health care provider attending a newborn infant to (A) notify
8 the infant's mother that there are expanded screening tests
9 for metabolic and genetic disorders that may be given to her
10 child in addition to those tests required by the State and
11 (B) provide that information to the infant's mother, in
12 writing, within 24 hours following the infant's birth.

13 By May 1, 2002, the Department of Public Health shall
14 develop and distribute to physicians and other health care
15 providers the written informational materials concerning
16 expanded screening tests described in the preceding
17 paragraph. The physicians and other health care providers
18 shall use the materials to provide the written information to
19 pregnant women as required under this subsection. The
20 information provided to such women must include, but need not
21 be limited to, the following:

22 (1) The benefits of the expanded screening.

23 (2) The disorders that are included within the
24 expanded screening.

25 (3) The time at which the expanded screening is
26 performed on a newborn infant.

27 (4) The manner in which the expanded screening is
28 performed, and information on follow-up procedures.

29 This subsection shall become inoperative upon the
30 Department's full implementation of a statewide expanded
31 screening program that is testing all newborn infants for all
32 detectable genetic and metabolic disorders.

33 (b) Maintain a registry of cases including information
34 of importance for the purpose of follow-up services to

1 prevent mental retardation.

2 (c) Supply the necessary treatment product where
3 practicable for diagnosed cases for as long as medically
4 indicated, when the product is not available through other
5 State agencies.

6 (d) Arrange for or provide public health nursing,
7 nutrition and social services and clinical consultation as
8 indicated.

9 (e) Require that all specimens collected pursuant to
10 this Act or the rules and regulations promulgated hereunder
11 be submitted for testing to the nearest Department of Public
12 Health laboratory designated to perform such tests. The
13 Department may develop a reasonable fee structure and may
14 levy fees according to such structure to cover the cost of
15 providing this testing service. Fees collected from the
16 provision of this testing service shall be placed in a
17 special fund in the State Treasury, hereafter known as the
18 Metabolic Screening and Treatment Fund. Other State and
19 federal funds for expenses related to metabolic screening,
20 follow-up and treatment programs may also be placed in such
21 Fund. Moneys shall be appropriated from such Fund to the
22 Department of Public Health solely for the purposes of
23 providing metabolic screening, follow-up and treatment
24 programs. Nothing in this Act shall be construed to prohibit
25 any licensed medical facility from collecting additional
26 specimens for testing for metabolic or neonatal diseases or
27 any other diseases or conditions, as it deems fit. Any person
28 violating the provisions of this subsection (e) is guilty of
29 a petty offense.

30 (Source: P.A. 83-87.)

31 Section 99. Effective date. This Act takes effect upon
32 becoming law.